

# MS and me

## a self-management guide to living with MS



We hope you find the information in this book helpful. If you would like to speak with someone about any aspect of MS, contact the MS Trust information team and they will help find answers to your questions.

This book has been provided free by the Multiple Sclerosis Trust, a UK charity which works to improve the lives of people affected by MS. We rely on donations, fundraising and gifts in wills to be able to fund our services and are extremely grateful for every donation received, no matter what size.

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The MS Trust offers a wide range of publications, including a newsletter [Open Door](#), which provides an ongoing update on research and developments in MS management. In addition it contains articles from people with MS and health professionals.

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## Introduction

When you are diagnosed with multiple sclerosis you are embarking on a lifelong journey. We hope this book will help you to understand more about your own MS and find the most effective ways to manage this wherever you are on that path. Living effectively with MS means using all the resources available to you, some of those will be within you, like setting yourself goals, and some of them will be external such as finding the information you need. The term often used for this is self-management.

To support you in managing your MS successfully we have included some practical strategies that we hope will be useful. Not everything will be helpful all of the time, there may be some things that are relevant to you now and some that might become useful later. But the aim of this book is to give you some ideas about how you can start managing your MS and living your life to the full.

# 1. What is self-management?

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Self-management is something you probably do all the time but don't realise it.

Every day you use problem solving skills - getting to that meeting when the car has broken down or sorting out after school activities for the children. You set goals and manage your stress and your time – this is self-management.

MS is unpredictable but you can learn to understand what affects your condition, how to make the most effective use of medication and build good relationships with the health professionals that work with you.

Self-management can enable you to control the things you can control and better deal with the things you can't. You are then best placed to face the challenges that living with this condition might bring.

Of the estimated 100,000 people living with MS in the UK the average time spent with a health professional is thought to be around three hours a year. Most people, most of the time, are self-managing their condition whether they know it or not. This doesn't have to mean "going it alone". Support from an MS specialist nurse, GP and other health professionals that you are in contact with along with friends and family, will help you make decisions about treatment and lifestyle choices that are right for you. Everyone's experience of MS is different and everyone's journey in self-management will also be unique.

**“Self-management is about knowing how to recognise the difficulties MS can bring and adjusting your way of life to accommodate them...finding new ways to live life to the full.”**

Nikki

### **In MS self-management includes:**

- dealing with symptoms and relapses
- making informed choices about medication
- making best use of available resources
- being a partner with health professionals in making decisions about treatment
- living well and accommodating MS into your life.

### **People who are most likely to successfully self-manage their MS:**

- have a good understanding of MS
- manage the impact of MS on physical, emotional, social and working life and are able to make adjustments when necessary
- actively participate in making decisions with health professionals
- adopt healthy lifestyles
- take action.

### **Adjusting to a diagnosis of MS**

The impact of a diagnosis of MS on people varies. Some people experience shock and disbelief whereas other people are relieved to have a diagnosis and feel pleased that at last somebody has recognised something is wrong.

The psychological adjustment to a diagnosis of MS might include an increase in feelings of anxiety, fear, anger or frustration, or disturbance of your moods.

As MS can cause physical and psychological changes that can affect many aspects of your life including work, social and family life, the reactions associated with a diagnosis of MS can be similar to those of loss and grief.

**“In my experience some people seem to consider that their life, before diagnosis with MS, was a time when they regarded themselves as “normal”, their true self. A coping strategy which I have adopted is to create a new normal. I have a new self which is not worse, just different. This attitude has enabled me to move forward with my life and stop getting bogged down with negative thoughts of what I used to achieve.”**

Rohan

It takes time to come to terms with a diagnosis of MS; this is a long-term condition and requires long-term adjustment. This can take great personal effort and require the support of friends, family and health professionals.

When you are first diagnosed with MS you might feel that information about self-management is not for you, it can be years later when this might seem relevant.

**“I accepted the diagnosis; in fact it was a relief to know what it was. It was over a year later that realisation hit me, this was for life.”**

Jim

#### **Other MS Trust resources**

Making Sense of MS – this resource is for people who have been recently diagnosed with MS.

[www.mstrust.org.uk/msoms](http://www.mstrust.org.uk/msoms)

Successfully adjusting to life with MS has been linked to learning strategies such as: being able to juggle good and bad days; pacing activities; delegating and prioritising tasks; and managing stress. In meeting the challenges of living with MS, people often find strength and courage that they did not know they had.

## How you think and feel about yourself

It helps to understand how you react to the ups and downs of life. Do you believe that what you do makes a difference and that your involvement is essential to maintaining your health? Do you have confidence in your ability to acquire the skills you need to meet challenging situations and persevere in difficult situations?

Linked to this is self-esteem; the respect, regard, value and opinion you have about yourself. This can be affected by MS in many ways; there may be times when you feel less confident. For example, the things you used to be able to do easily might be more difficult now. It can also affect your self-image and at times you might feel less of a person, less of a partner and less useful to your family and friends. The way that people treat you may change.

**“After I told my neighbour that I had MS she would cross the street so that she didn’t have to talk to me.”**

Elizabeth

However, successfully meeting the challenges that living with MS inevitably brings can have a positive impact on self-esteem and build your confidence to go forward into new situations. Finding different ways of doing something rather than giving up altogether can also increase your feelings of being in control.

**“Getting the diagnosis of MS was the kick start I needed to review my life and my work – I wouldn’t have done that if I hadn’t been jolted into action.”**

Hellie

Many factors can affect how you apply self-management skills and this is likely to be different at different times. Changes in relationships, for example asking for help when you have previously been self-sufficient, may impact on your confidence.



On the other hand, recognising that you need help and being able to ask for this can be a positive step in self-management.

### Ways to build and maintain self-esteem and a positive outlook include:

- feeling involved
- being realistic and flexible
- recognising that you are loved and cared for by other people
- using activity and exercise to improve your fitness, your sense of wellbeing, and lift mood.

### “Getting involved with a voluntary group helps me feel useful and needed.”

Beth


### Taking a positive approach

A person with a positive approach recognises the negatives that crop up day to day but develops the skills and coping mechanisms to handle them. Although some of the consequences of MS cannot be controlled it is important to recognise what can be managed and, as MS is a long-term condition, these have to be managed on a daily basis.


Just looking at things from a different point of view can be helpful, for example:

‘Today I’ve got to do x...’ sounds as though you’re acting for someone else whereas saying ‘Today I’ve decided I want to do x...’ puts you in charge. When problems arise, you could describe them to yourself and to others as ‘opportunities’ or ‘challenges’ that you can learn from. This technique is known as re-framing – changing your feelings about events by setting them in a new perspective.

 I'm totally shattered, but I can't relax because I still have to do the dishes.

 I'm tired now so my priority is to rest. The washing up can wait until later.

 My walking is slow.

 I'm in no rush to get where I'm going. Getting there safely is what matters.

Identify and challenge negative thoughts and behaviours.

## 2. Self-management techniques

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Monitoring your MS, setting goals and solving problems can all be valuable strategies in managing your MS.

### Knowledge is power – monitoring your MS

The idea of self-management is based on understanding your own MS, so keeping track of changes and what might bring these about is a key tool. This can help you to identify trigger factors and patterns, for example finding fatigue is more severe on a hot day or that your fatigue might be worse at a particular time of day or after a particular activity. Becoming aware of this allows you to plan your work or activities effectively around this.

One way to achieve this better understanding is through becoming aware of changes in your MS.

Keeping a diary specifically to monitor your MS can be a helpful tool, recording how your MS alters in response to different factors such as: activity levels; stress; diet or at different times. This information will allow you to understand what affects your MS and how. This knowledge will help you, your family and your health professionals to manage your MS effectively.

Apps can also help you to monitor symptoms some of which include an interactive symptom tracker and this information can be illustrated using easy to read charts. Other features can enable you to record medication and set reminders for taking them, log contact details of your MS team and identify factors which could make symptoms worse such as weather. This can then be shared with your MS team. The SymTrac app is one example and can be downloaded from [www.symtrac.com](http://www.symtrac.com) and is available for both iPhone and Android platforms.

## Useful information to keep in your personal diary might include:

- Information about relapses you have experienced for example the date the relapse started; how you felt immediately before the relapse; when things started to improve; the symptoms you experienced; what helped; whether you were prescribed steroids either orally or by infusion and any side-effects of this treatment; if you were admitted to hospital; how long the relapse lasted; if you had a full recovery or were left with some residual problems.
- When a new symptom was experienced.
- Symptom changes and any related factors for example if it was a hot day.
- Questions you would like to ask your health professional either by telephone or at your next appointment.
- Prescription medication you are taking, and any medication you have previously tried. It is also useful to note what effects the medication has had and any side-effects.
- A copy of your MRI scan reports. You can ask your consultant or MS nurse if you can have a copy of these.
- A copy of the results of any other investigations undertaken such as lumbar puncture or blood tests.
- A copy of letters between your GP and other health professionals including hospital consultants. This keeps you informed, helps you to remember what was said and is a reminder of when you are due to be reviewed.

This might be very informal as Hellie's diary illustrates

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**Friday 7 May**

Yesterday I was so tired and achy I didn't know what to do with myself. Dinner was easy, just to shove something in the oven for 20 mins. I was so far gone in fatigue-land it was like my sofa was keeping me prisoner. When I get tired like this, I have huge concentration difficulties and problems finding words - Does anyone else? Ask on MS people discussion list.

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**Saturday 5 June**

This week fuzziness in my leg has moved up to my arm. Had some pains in my hand also one day, but it has been mostly ok. It mostly feels like both arm and leg is slightly "weaker" and fizzy compared to the left side. Must remember to mention to Sally (MS nurse) on Tuesday.

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**Saturday 4 September**

I've not slept very well for a few weeks now and it is getting worse and worse. At the moment my eyes are aching as if I rubbed soap into them, and my eyelids are heavy like they are made of lead. I guess some of this lack of sleep comes from worrying about getting the new kitchen put in but its making fatigue even worse!

Or may be more structured:

### MS relapse details

When was the relapse? \_\_\_\_\_

What were the symptoms? \_\_\_\_\_

How were they treated? \_\_\_\_\_

Resolved: Yes  No

### Medicine details

Drug name \_\_\_\_\_

Dosage \_\_\_\_\_

What was it prescribed for \_\_\_\_\_

Commencement \_\_\_\_\_ Date completed \_\_\_\_\_

### Monthly summary

Questions to ask MS nurse

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

### Hospital appointments

Date \_\_\_\_\_ Time \_\_\_\_\_

Place \_\_\_\_\_ Appointment with \_\_\_\_\_

Action \_\_\_\_\_

Talking points \_\_\_\_\_

## Goal setting

Setting goals gives you focus and a sense of achievement when they are reached. It can be an important tool in self-management.

Your goal should be important to you, something which you can achieve within a specified time limit and which will help you to better manage your MS.

In each case:

- decide what you want to achieve
- look for different ways to achieve your goal
- make an action plan which incorporates milestones to check your progress along the way
- use the action plan
- review the results
- make changes
- reward yourself - celebrate your successes and congratulate yourself on your achievements.

**“Fatigue was always a huge problem for me. I made a positive decision to tackle this and the fatigue has improved – the reward for having less fatigue is being more active than ever before.”**

Carole

## Make your goals SMART:

- S**pecific I want to feel less fatigued at work.
- M**easurable Something that you can attain and will know when you have achieved this; you can monitor the times you feel fatigued by keeping a diary.
- A**chievable Is the goal within reach? Feeling less fatigued at work is a good goal whereas eliminating fatigue altogether is unlikely to be achievable.
- R**ealistic Can I actually do this?  
Yes by using a number of strategies.
- Consider a regular exercise programme that increases your heart rate for 15-20 minutes three times a week or more.
  - Look at your diet. Do you snack on crisps, chocolates and biscuits? If so change these to fresh or dried fruits and ration treats to one or two a day.
  - Do you use sugar or caffeine to boost your energy levels? If so consider alternatives.
  - Use lunch time to rest instead of shopping, shop online.
  - Consult the MS Trust book **Living with fatigue: a guide to fatigue management for people living with MS** for more hints and tips.
- T**imed Set a manageable time limit so that you won't lose interest but you do have enough time to achieve your goal. Three months might be reasonable in this example. Break the task down so that you have smaller goals or milestones along the way and review your progress as you go.
- One month review - Are you on target to reach your goal? If not, make those changes to your strategies. Decide on a treat so that when you reach your target you have a reward to look forward to.



### Other MS Trust resources

Living with fatigue: a guide to fatigue management for people living with MS.

[www.mstrust.org.uk/fatigue](http://www.mstrust.org.uk/fatigue)

**“I find I can achieve more when tasks are divided into ‘chunks’ and I rest in between than when I work straight through until my fatigue becomes overpowering. Nine times out of ten when I work straight through, I do not complete my allotted task.”**

Alice

## Problem solving

There are many approaches to problem solving which can help you to conduct a rigorous analysis of the problems you face. By helping you to look at them in a structured and methodical way these skills can give you a good starting point in problem solving where you might otherwise feel overwhelmed by a situation.

**“Each problem that I solved became a rule which served afterwards to solve other problems.”**

René Descartes (17th Century philosopher)

Identify the problem	I'm exhausted by the time I reach work
Why?	I drive in the rush hour
Why?	Work begins at 9am

### List ideas to solve the problem

Here it can be helpful to look for the best of what has happened in the past, and what is currently working well. Involve as many people as possible, for example family, friends, a discussion group or colleagues, to examine different approaches.

If you are exhausted after driving to work you might consider; taking public transport - getting a taxi - sharing a lift - travelling at

a different time – starting work later or earlier - working from home. Contact Jobcentre Plus to find out about Access to Work, the Government scheme that can pay towards the cost of getting to work if you cannot use public transport.

### Select a method to try

Selecting the method and putting this in to practice can take some time so allow a reasonable timescale.

For example:

**Take a taxi** - find out about the availability of the taxicard scheme (this is a subsidised transport scheme run by some local councils) - allow one week.

**Arrange for the taxi service to and from work** - allow one week. Use service for four weeks. Consider the results - what did I achieve - what went well - has my problem been solved?

**Try another idea if you need to** - examine what was good and what was not so good.

Keep going! It may take you some time to find the solution that works best for you.

# 3. Self-management in action

This section considers how the strategies and techniques examined earlier can be used to help you to effectively manage your MS.

## Recognising a relapse

Experiencing a relapse can bring home the diagnosis of MS again. This may mean a time of readjustment as the new symptoms impact on family life and work for an unknown period of time, and with an unknown outcome. As part of this adjustment process the grief, anxiety, anger and guilt you might have felt at diagnosis may well up again and make you doubt your ability to deal with your MS and feel out of control.

In the early stages of MS it can be difficult to recognise what might be a relapse and what is a fluctuation of your symptoms. However with experience, as you get to know your own MS, and using monitoring tools such as a diary or app, this will become easier to recognise.

### You may be having a relapse if:

You develop new symptoms or your symptoms get worse and last for more than a day. Your healthcare professional should check that nothing else could be causing these symptoms, such as an infection, and confirm your diagnosis with a health professional with expertise in MS.

*NICE MS Clinical Guideline 186 (2014), Information for the public.*

A relapse can be considerably longer than 24 hours and may go on for weeks or months. The frequency of relapses, the severity of symptoms and the length of time between attacks are all unpredictable. Symptoms may vary greatly. They may be symptoms that you have had before or new symptoms. You will learn through time and with experience more about your own relapses.

### What to do if you think you are experiencing a relapse:

Contact your MS specialist nurse service or another health professional.

You may then:

- receive oral steroid treatment from your GP
- be referred to the relapse clinic in the hospital
- agree to monitor yourself to find out if symptoms improve naturally
- receive treatment for any underlying infection.

**“You know your own MS so don’t be put off if you feel you need to speak with the nurse or doctor. Don’t accept “no” just to please other people.”**

Jill

## Dealing with symptoms

After diagnosis you might attribute everything to MS or conversely, believe that nothing is MS because you don’t want it to be – you will learn about your own MS over time.

Understanding what might act as a trigger to cause worsening of your symptoms is a large part of understanding your own MS and being better able to manage it. Your own understanding will improve with time and experience.

Gill had a sudden increase in her leg spasms. When she and her MS nurse together considered what was happening they discovered a blister that had been caused by wearing new training shoes. This was triggering the spasms and when the blister healed, spasms reduced.

Other factors can also have an impact on symptoms. For some people heat can make symptoms worse.

**“In the summer, the heat makes me much more sluggish and I have to try to keep as cool as possible, I have air con in the car and a humidifier at home. As long as I stay cool I don’t slow down too much.”**

Vicky

### **Other MS Trust resources**

Spasticity trigger diary.

[www.mstrust.org.uk/spasticity-triggers](http://www.mstrust.org.uk/spasticity-triggers)

Urinary tract infections (UTIs) can be common in MS, and may make MS symptoms worse or trigger a relapse. Talking to your GP or other health professional about checking for a UTI if you are generally feeling unwell can be helpful.

You might find symptoms increase if you have another virus or infection. Avoiding contact with viruses and infections where possible, especially following steroid therapy for a relapse is important.

Ensuring that you have the vaccinations required if you are travelling abroad and for seasonal flu in the UK will prevent you contracting avoidable and potentially serious diseases.

Keeping a record of when your symptoms change for example using a diary as explored in the earlier section **Knowledge is power – monitoring your MS** will allow you to recognise what might be a relapse and how your symptoms fluctuate.

## **Making treatment choices**

Ideally a decision about what treatment is right for you will be reached through considering the benefits you might expect from the treatment and any potential associated risks. This includes the effect a treatment may have on your lifestyle such as when

and how medication or a course of treatment is taken. Your commitment to stick to the course is also an important factor.

Treatment could be medication such as a disease modifying therapy, a course of physiotherapy or treatment for a specific symptom.

#### Questions to consider when discussing treatment options:

- Why will this treatment be good for me?
- What are the different types of treatment options?
- How long can I take to decide what treatment I have?
- What does the treatment aim to do? When and how will I know if the treatment is being effective?
- What if the treatment doesn't work?
- Are there any side effects or risks?
- Who will manage my treatment?
- Is there any written material about the treatment options?
- Is there anything else I can do to help myself?
- What are the implications of delaying treatment?

Making a decision is ideally done in partnership with your health professional. If the goals of the treatment are relevant to you, they are more likely to be successful than if you “go along” with whatever might be suggested by your health professional because you don't want to cause trouble.

Most health professionals want to help with what's important to you but will only know if you tell them.

Patient decision aids can also be useful. These tools are designed to help people become involved in decision making by providing information about the options and outcomes and helping to clarify your personal values.

They are designed to complement input from a health professional. MS Decisions [www.msdecisions.org.uk](http://www.msdecisions.org.uk) is an online decision aid designed to support decision making around the disease modifying therapies.

There may be some times when you would like more support making decisions and others when you want to be more independent.

**“Advise me fine – the decision is all mine.”**

Carole

**“Being fit I put MS on the back burner, I didn’t want any drugs, didn’t want anything.”**

Man with MS – (Taking Control survey)

You may decide on reflection that the time is not yet right for you to start on a course of treatment. However, make sure that you know the consequences of deciding not to take a particular course of treatment and remember that “No” is not forever, a time may come when you wish to change your decision.

Medication can be a constant reminder of your MS, especially when you feel well.

It can be difficult if you are taking a number of medicines, for example to manage different symptoms, to take them all so that they act effectively. One man managed his medications in the following way:

- Measured tablets for next seven days and put them into a medicine dispenser to ensure correct dosage.
- Kept a diary of when repeat prescriptions were fulfilled and diarised requests for two weeks before needed.
- Used prescription collection and delivery service so did not have to go to the surgery if feeling unwell.

- Kept a seven day emergency supply of tablets separate from general supply.
- Arranged with GP to align drugs so that they could all be ordered at the same time.
- Attended a medicines review at local pharmacy and built up a good relationship with pharmacist so that changes in medication could be discussed and also felt confident to ask about drug interactions and side effects.
- Every three months carried out audit of medicine cabinet and returned drugs no longer required to the pharmacy.

## Utilising resources – the value of information

It has been said that the key to successfully living with a long-term condition like MS is the right information, at the right time, in the right format. This is supported by government policy and is at the heart of the NHS Constitution.

You have the right to be involved in discussions and decisions about your healthcare and be given information to enable you to do so.

*NHS Constitution (2013).*

Good quality information in a suitable format supported by guidance from a health professional has been shown to increase people's levels of confidence in the decision making process and reduce anxiety and isolation.

Whilst many people like to have all the information they can obtain about MS, other people restrict what they want to see and a few do not want any information at all. There is no one right way and your need for information is likely to change over time.



### Where can I access information?

There are many sources of reliable information available including your health professionals; voluntary organisations; the public library - particularly a health information point; social services and the Patient Advice and Liaison Service (PALS) at your local hospital. The **More information** section has further details.

### How to assess the quality of information

There is an abundance of information available about MS. A search for multiple sclerosis on Google finds over 800,000 results from UK sources alone, however quality is variable and it can be difficult to decide which information is to be trusted.

When assessing information from any source, either books or the internet, questions to ask include:

- **Reliable** - how authoritative are the authors, do they know what they are talking about? Do other trusted sources agree with this information? Is this referenced?
- **Up to date** - what are the main sources of information used to compile the publication, what is the date of publication and any revisions? On the internet when was the website or page last updated or reviewed?
- **Balanced and unbiased** - is there a clear indication of whether the publication is written from a personal or objective point of view? Be wary if the publication focuses on the advantages or disadvantages of one particular treatment without reference to others; if the publication relies primarily on evidence from single cases; if the information is presented in a sensational, emotive or alarmist way or if the authors have something to sell.

The Information Standard is a certification programme for all organisations producing evidence-based health and care

information for the public. Any organisation achieving The Information Standard will carry the quality mark. This shows that it has undergone a rigorous assessment to check that the information they produce is clear, accurate, balanced, evidence-based and up to date.



## Working in partnership with health professionals

An effective partnership is the key to ensuring that you and your health professionals are working towards goals that you all share to improve or maintain the quality of your life in ways that are relevant to you. This collaborative partnership is about shared responsibility and moves away from the old emphasis of a medical authoritarian approach. Whilst a neurologist may be an expert in MS, you are the expert in your MS and how it affects your life.

Increasingly, health professionals are committed to working in partnership but it is fair to say that not all health professionals are comfortable with this.

Studies have also shown that not everyone with MS wants to be an equal partner in making decisions and it is up to you to decide the level of involvement that you want to have.

This is likely to change over time and may be dependent upon the decision being made and how you are affected by your MS at that time.

In order to be a partner in decisions about your healthcare it is vital that you have all the information that you need to help you to talk with your health professionals and make informed decisions.

It can be helpful to think about questions in advance and write them down. Opposite are some examples of the things that can be useful to ask.

### Questions to ask:

- Can I check that I've understood what you said? What you're saying is . . . reflect back what you thought was said.
- Can I be referred to an MS specialist? Is there a choice of places I could see them? Is there an MS specialist nurse, physiotherapist, continence advisor, occupational therapist? How can I make contact with them?
- Can I have a copy of any letters written about me?
- Are there any services I would benefit from while I am waiting for a specialist appointment?
- Is there anyone in my situation I could talk to while I am waiting for a specialist appointment?
- Is there any written material available about managing this symptom?
- What happens next – do I come back and see you?

Don't be afraid to ask for things to be written down and a second pair of eyes and ears such as a partner or friend can be helpful to capture all the information. You could make notes yourself or even record the session.

If you find it difficult building a partnership with a particular health professional you can ask to see someone else. Not everyone gets on with everyone else; this is not necessarily a failing on anyone's part.

# 4. Living well

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Many people feel that ensuring they remain as healthy as possible puts them in the best position to deal with the challenges that MS brings.

Whilst MS itself is unpredictable a healthy lifestyle can have a positive effect on how it impacts on your day to day life.

Positive ways of staying healthy when living with MS include:

## Activity and exercise

Exercise encompasses any activity that involves physical movements with even a slight increase in effort, such as stair climbing, housework, shopping, gardening or decorating. A combination of 'exercise' and 'activity' may be the best approach considering fluctuations in MS from day to day. It is also important to know when to rest and when to pace activities.

**“Listen to your body – rest when you need to.”**

Mary

Exercise improves both general physical and emotional health as well as improving fitness. It releases good chemicals and makes us feel more in tune with our bodies and elevates mood. Research has shown specific benefits of exercise for people with MS including reduced fatigue levels and improved strength, mobility and bowel and bladder function.

**“When people said exercise gives you energy, I laughed. I gave it a try and I’ve never felt more alive.”**

Anne

Alternatively you may want to find an activity that isn't too energetic. There are lots of activities, enjoyed on your own or in a group, which can provide you with some gentle exercise and contribute to your wellbeing.

### **“Exercise when you are at your best.”**

Trudy

Tips for exercising:

- Devise a programme that works for you either with your physiotherapist, at the gym or at home.
- When you start your programme don't go mad and try to do all the exercises at once, particularly if you haven't done much recently.
- Pick out a couple of exercises that you know you will be able to do and build up gradually. There's no point in setting your target so high that you will not be able to reach it.
- Pick a day in the week and a good time in the day - not when you feel at your lowest!
- Modify your exercise regime as you need to.
- Some people find exercising in a group can be motivating and fun.

#### **Other MS Trust resources**

Exercises for people with MS.

[www.mstrust.org.uk/exercises](http://www.mstrust.org.uk/exercises)

Move it for MS – a free DVD of exercises.

## Food and drink

No specific diet has been proven to be beneficial for people with MS. However, there has been research into a healthy diet for other conditions, notably cardiovascular disease, which is much more common than MS in the general population.

A healthy well balanced diet and plenty of fluids are important for optimum energy levels. A high fibre diet can prevent constipation which can affect symptoms for example spasticity and spasms may be made worse and bladder symptoms aggravated. Good nutrition can also reduce the physical risks of weight gain, such as heart disease and high blood pressure. Gaining weight can also affect emotions and result in a loss of confidence and self-esteem in addition to making mobility problems more difficult to manage.

### **Other MS Trust resources**

Diet factsheet.

[www.mstrust.org.uk/diet](http://www.mstrust.org.uk/diet)

Adequate fluid intake is essential to prevent dehydration and is particularly important where bladder or bowel problems exist. Too little fluid can increase the risk of urine infections, tiredness, headaches, constipation, and so possibly worsen existing MS symptoms. Recommended guidelines are one and a half litres, or eight glasses, of fluid a day. Drinks that contain caffeine such as tea, coffee, cola and some soft drinks are best limited, for example to a maximum of four mugs of coffee a day. Caffeine can also irritate the bladder and the same is true of alcoholic drinks.

## Health awareness

People with MS remain at risk from the same health concerns as the general population. For this reason it is important to recognise changes in your health and not just assume that all

changes are MS related, monitoring your MS for example with a diary, will help with this.

Regular health checks and attendance at screening programmes such as cervical smear tests and well woman/man clinics in addition to breast or testicular examination are important.

In addition to the known health risks associated with smoking such as cancers and cardiovascular disease, studies have suggested that people with MS who smoke experience more rapid disease progression than non-smokers.

**Other MS Trust resources**

Smoking – A-Z of MS.

[www.mstrust.org.uk/smoking](http://www.mstrust.org.uk/smoking)

# 5. Barriers to self-management

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The feelings of grief and loss that can be part of living with MS can act as a potential barrier to self-management, but recognising these as part of the condition can be helpful.

Stress, depression and anxiety also reduce the ability to cope and will therefore have an impact on successful self-management.

## Stress

Many people with MS find that managing symptoms and living with the restrictions and uncertainty imposed by MS is itself stressful. Minimising stress is a good goal when living with MS although some stress can be good and to avoid all stress is impossible. When stress begins to impact in a negative way, there are strategies you can adopt to manage this.

**“Often priorities will change with MS and things that used to cause stress may no longer do so.”**

Carole

The most commonly accepted definition of stress is that it occurs when a person believes that “demands exceed the personal and social resources the individual is able to mobilise”. It’s when things feel out of control and it is the interpretation of a situation that drives the level of stress that you feel.

Living with MS may require better coping strategies to deal with stress:

- Managing your time effectively and breaking tasks down can help to reduce stress and allow you to feel you have achieved something in your day.



- Prioritise – tackle the most important things first and know the difference between urgent and important.
- Some people respond well to relaxation tapes, whilst others find stress relief from exercise, particularly aerobic exercise which increases your heart rate for example cycling, walking, using a treadmill or swimming. Exercises which involve stretching and strengthening the muscles such as Yoga, Tai Chi and Pilates also help to reduce stress.
- Listening to music, meditating, reading or listening to a book on CD are also ways in which to relax.

Keeping a stress diary can be a useful coping strategy:

Look at the different stresses you experience and list them by frequency with the most common at the top. Make another list with the most unpleasant stresses at the top. If you look at both lists the stresses at the top of each are the ones that are most important for you to learn to control. You can use the diary to find out the situations that caused the most stress to learn which stressors you cannot change and to look for ways to cope with them.

**“I try not to worry too much about the things that I cannot change. Not always possible, I know! There are usually ways around problems and I’m lucky, I have a supportive husband and really good friends.”**

Viv

A job list can be useful:

Job

Action

Fred’s birthday

You’ve got the card - write and post it

Collect prescription

Essential – next time consider delivery service

Library books due

If no time, call or go online to renew

## Depression

It is estimated that about half of all people with MS will experience depression at some stage. There are two reasons for this: one is caused by MS itself and the other is caused by living with a long-term condition. However, it is still widely believed that there is a stigma attached to experiencing depression.

**“Going to see your GP and being diagnosed with depression should not be seen as having failed. Recognising your problems and accepting help is a positive step in managing your MS.”**

Liz

The following may be signs of depression and if you experience any of these you might want to talk to your doctor or MS nurse:

- persistent sadness lasting more than two weeks, or unexplained tearfulness
- altered sleep patterns - finding it difficult to sleep or sleeping too much
- feelings of hopelessness, guilt and low self-esteem – you lose interest in personal care and the way you look
- reduced energy and inability to concentrate or take pleasure in anything
- social withdrawal
- thoughts of suicide or death.

### **Other MS Trust resources**

Depression factsheet.

[www.mstrust.org.uk/depression](http://www.mstrust.org.uk/depression)

**“It was a close friend who recognised my depression and suggested I talk to my GP.”**

Liz

**“I discussed how I felt with my MS nurse and my GP – there is medication which helps.”**

Jenny

**“Some people feel that there is a stigma in taking anti-depressants. The support group I am involved in refer to anti-depressants as Happy Pills, as they really are helpful.”**

Liz

## **Anxiety**

Living with MS can be a source of anxiety regardless of any specific medical problems. Altered life circumstances and not knowing how you will feel from day to day, or from morning to afternoon, are significant causes of anxiety.

Anxiety can cause a physical response that produces symptoms such as tiredness, weakness, the urge to go to the toilet and a blurring of vision.

All of these are similar to symptoms of MS so it may be difficult to tease out what is caused by anxiety and what is due directly to your MS.

Too much caffeine in your diet can make you more anxious than normal and caffeine can disrupt your sleep and speed up your heartbeat. If you are tired, you are less likely to be able to control your anxious feelings. Smoking and alcohol can also worsen feelings of anxiety.

## Overcoming the barriers

An MS nurse can help through encouraging you to develop self-help strategies such as relaxation techniques, discussing fears or distraction techniques. Some things to consider might also be whether these symptoms might be side effects of any medication that you are taking and to be aware that alcohol can also create low mood and make you more anxious.

Many people find that daily contact with family and friends, doing something they love like going to watch a film, meeting a friend for coffee or a chat or a trip to a favourite place, are helpful in improving mood.

Cognitive behavioural therapy may also be useful for depression and anxiety. This is based on the belief that how we think about a situation influences how we act, and our actions subsequently influence how we think and feel. It encourages the adoption of new thinking and behavioural techniques.

Taking regular exercise and learning how to relax is also important. You may find relaxation and breathing exercises helpful, or you may prefer activities such as Yoga or Pilates to help you unwind.

## 6. Helpful hints

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Over time people find many ways to adapt and find the best ways of coping with and managing their own MS. Here are some hints and tips from people who have learnt to live with their MS.

- Give yourself a treat when things are difficult or you have coped at a stressful time.
- Take up a new interest or hobby, something you've always wanted to try. This is a good way to meet others and take your mind off the day to day stresses that we all face.

**“I took up photography a couple of years ago and love it. On a good day I can go out and take photographs and on a not so good day I relax in bed and play with them on the computer.”**

Jane

Take some regular exercise. This doesn't have to be extreme. Even getting off the bus one stop early, or parking at the other end of the car park and walking the rest of the way can make a difference.

- Rest is not failure – resting is a coping strategy.
- Take each day as it comes. Try not to despair if you are having a really bad day – the chances are tomorrow will be easier.
- Be honest and open about how you feel. If you go through a bad patch talk to someone, be it family, friend or health professional. It really can help to share your feelings.
- Try to unwind when you are stressed - have a relaxing bath or go for a walk. You may find Yoga, massage or aromatherapy useful.
- Make sure you get a good night's sleep - but don't get too upset if you can't sleep, have a warm milky drink and listen to some relaxing music.

# 7. More information

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## Self-management courses

There are many self-management courses available. Some are for a variety of different long-term conditions and some are MS specific. Courses aim to teach you skills to boost your confidence and live well with your condition.

For information about self-management courses around the country visit the self-management UK website [www.selfmanagementuk.org](http://www.selfmanagementuk.org)

## Expert Patients Programme

The Expert Patients Programme is a free six week course for anyone living with a long-term health condition. The programme aims to provide support and develop self confidence to help you feel more in control. Your local NHS community healthcare organisation can help you find courses in your area or you can Google 'Expert Patients Programme' and the town or city where you live.

## MS specific self-management courses

Your MS specialist nurse or occupational therapist may also run self-management programmes, or courses on managing specific aspects of MS such as fatigue.

### **Other MS Trust resources**

Find your MS specialist nurse on the Map of MS Services.  
[www.mstrust.org.uk/map](http://www.mstrust.org.uk/map)

## Information from the MS Trust

### MS Trust Information Service

If you have specific questions on any aspect of MS, contact our team of information officers on 0800 032 3839 or [infoteam@mstrust.org.uk](mailto:infoteam@mstrust.org.uk)

MS Trust books and factsheets are free and can be ordered by ringing 01462 476700 or by email at [info@mstrust.org.uk](mailto:info@mstrust.org.uk)  
All titles can be read or ordered online at [www.mstrust.org/pubs](http://www.mstrust.org/pubs)

Keep up to date with news about research and the world of MS by signing up for Open Door, the MS Trust's free quarterly newsletter, or our weekly email alerts. Ring 01462 476700, email [info@mstrust.org.uk](mailto:info@mstrust.org.uk) or signup online at [www.mstrust/in-touch](http://www.mstrust/in-touch)

### Other resources

- **A-Z of MS**  
this covers a wide range of information about symptoms, management and sources of support  
[www.mstrust.org.uk/atoz](http://www.mstrust.org.uk/atoz)
- **At work with MS**  
[www.mstrust.org.uk/at-work](http://www.mstrust.org.uk/at-work)
- **Diet factsheet**  
[www.mstrust.org.uk/diet](http://www.mstrust.org.uk/diet)
- **Depression factsheet**  
[www.mstrust.org.uk/depression](http://www.mstrust.org.uk/depression)
- **Living with fatigue**  
fatigue management for people with MS
- **Making Sense of MS**  
a resource for people who have recently been diagnosed  
[www.mstrust.org.uk/msoms](http://www.mstrust.org.uk/msoms)

- **Map of MS services**  
[www.mstrust.org.uk/map](http://www.mstrust.org.uk/map)
- **StayingSmart**  
a resource to help you understand and manage cognitive problems  
[www.stayingsmart.org.uk](http://www.stayingsmart.org.uk)

#### Online support

- **MS people UK**  
An online community for those with MS, their families and friends  
[www.ms-people.com](http://www.ms-people.com)
- **MS Trust online communities**  
Facebook group, twitter and blogs  
[www.mstrust.org.uk/interactive/socialnetworks/](http://www.mstrust.org.uk/interactive/socialnetworks/)



# Notes

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## About the authors

### **Nikki Embrey**

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Nikki has extensive experience of working with people living with MS and is passionate about supporting people to gain the skills necessary to become effective in self-management. Nikki highlighted a need for this publication to encourage people to become partners with their healthcare professionals and make decisions about treatment and lifestyle choices that are right for them.

### **Lynn Fox**

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The MS Trust is a leading independent UK charity for people with MS, their family and friends. The MS Trust Information Service provides a personalised enquiry service: produces many publications; Open Door, a quarterly newsletter; and web based information. Contact us to receive free information.

### **Thank you to**

All the people affected by MS who have shared their experiences in the development of this book to help others become confident in living life with MS to the full.

Please contact the MS Trust information team if you would like any further information about the reference sources used in the production of this publication.

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